

**2003 ANNUAL REPORT
STATE ADVISORY COUNCIL ON AGING
Lilo Hoelzel-Seipp, Ph. D., Chairperson**

**Policy and Program Recommendations to the
Michigan Commission on Services to the Aging**

April 2003

**JENNIFER GRANHOLM
GOVERNOR**

**State of Michigan
OFFICE OF SERVICES TO THE AGING
Lansing**

April 2, 2003

Dear Chairman Johnson and fellow Commissioners:

It gives me great pleasure to transmit to you the 2003 Annual Report of the State Advisory Council on Aging. In response to the Commission's charge, the Council has gained a greater understanding and knowledge of family caregiving. Since caregiving by family members is increasing in numbers and importance, it's a timely issue with tremendous significance for Michigan's aging population. The family caregiver is a key component to ensuring frail older adults' independence and dignity. I believe you will find this report informative and appreciate your thoughtful consideration of the Council's recommendation.

On behalf of the Council, I wish to thank the Office of Services to the Aging for providing information and support this past year. OSA's interest in and participation with the Council on this issue proved invaluable. I also extend gratitude to the guest Commissioners who shared their time and talents by attending a Council meeting.

Finally, thanks to the Commission for allowing me the opportunity to work with State Advisory Council. Please know that the Council deeply appreciates your interest and support.

Sincerely,

**Lilo Hoelzel-Seipp, Ph. D.
Chairperson
State Advisory Council**

Caregivers: They Are We

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Caregivers: They Are We

The State Advisory Council recommends that the Commission increasingly focus on caregiver needs in addition to those of the care recipient. The Council identified the following areas as components essential to supporting caregivers.

- 1. Assist caregivers to identify themselves as such**
- 2. Identify what the caregiver can expect**
 - a. from the care recipient;**
 - b. from service providers; and**
 - c. in relation to their own self-care needs**
- 3. How to find and obtain services**

Executive Summary

The State Advisory Council recommends that the Commission increasingly focus on caregiver needs in addition to those of the care recipient. The Council identified the following areas as components essential to supporting caregivers.

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After meetings filled with information on caregiving and in-depth discussion of problems and their solutions, the question was asked: who in this room is or has recently been a caregiver of an older person? Virtually every person raised a hand. The Council was not discussing a hypothetical problem or an abstract concept; the members were talking about a shared situation that is simultaneously universal and unique.

It is not surprising that, in the development of their recommendation, members focused on the needs of the caregiver, rather than care recipient. This focus was not intended to diminish the needs of the care recipient, but to elevate the caregiver to equal importance.

The Council was frequently reminded by presenters and resource materials that one of the most basic problems in providing help to caregivers is whether or not they perceive themselves as caregivers. Many people fulfilling caregiving tasks think of themselves primarily as loving spouses, caring offspring or devoted friends. They are doing what needs to be done and spend little, if any, time considering what their involvement is called.

Reviewing materials, presentations and other resources, the Council members drew upon their own knowledge and understanding of the task.

Nearly one of four households in the nation provides caregiving support to a person age 50+. As one presenter stated, every individual falls into one of three categories: current/recent caregiver, an eventual caregiver or a care recipient. The Council was reminded that research in family caregiving as early as 20 years ago identified family caregiving as a "normative life role." Everyone can expect to become a caregiver sooner or later. Caregivers' needs are still emerging. The needs of caregivers are as varied as the needs of the care recipients; there is no one service suitable for all caregivers. Like the role itself, "caregiver support" is often defined by the person who is the caregiver. Caregiving issues will become clearer as the experience is shared by more people.

The State Advisory Council on Aging recommends a clear focus on caregiver needs, as well as those of the care recipient. The role and tasks of caregiving are variable and responsive to the needs of the care recipient. The aging network has historically focused its attention on the needs of the frail older adult. The Council supports the recent state and federal initiatives that address the needs of the caregiver as well.

In previous reports and recommendations, the Council identified the important role played by information, referral and assistance services. The ability to find services through an information and assistance resource was cited many times as the point of connection between family caregivers and services. The Council encourages information and assistance resources to provide the requested service referral during an initial phone call/contact. Family caregivers are likely to be frustrated with a system that is not responsive to their inquiries.

It is clear that many family members do not perceive themselves as caregivers even as they perform caregiving tasks. Failing to identify themselves as caregivers can lead them to overlook supports aimed at assisting them. Dr. Rhonda Montgomery's recent caregiver research describes the evolution of the caregiver's identity and role. The self-identification as a caregiver occurs at different points for family members. In order to help people to identify their tasks as caregiving, the Council encourages the aging network to be familiar with Dr. Montgomery's work, presented at an Administration on Aging Caregiving Conference (see Appendix A).

As family caregivers, some people often fail to fully understand the challenges before them. The Council supports efforts that assist caregivers to understand and anticipate the changing needs of the care recipient. For example, the Council heard a presentation describing key differences between caring for a physically frail older person and one who has a dementia. Caregiver support should include knowledge about what to expect.

People often lack interest in services that do not apply to them. Knowledge about caregiving and support services become important when services are needed. The Council recognizes that family members/caregivers often do not know about the range of available services or where to look for them.

Service terms, such as respite, may not be understood by the target population of caregivers. Problems understanding the "language of caregiving" and identifying oneself as a caregiver were resolved in the OSA caregiver study that relied on a pragmatic approach to identify caregivers, e.g., "Do you help someone with their medications?" Caregivers need to have ready access to service information, presented in a clear manner, and understand the costs and benefits of service participation.

Caregiver of Today;

A family caregiver is anyone who provides assistance to someone else who needs it. It may be a spouse, adult child, aging parent or sibling. Family caregivers are unpaid individuals who provide an array of assistance, from paying bills to assisting with dressing/grooming to round the clock assistance with daily activities. Nearly one out of every four U.S. households (23%) has been involved in caregiving for a person aged 50 or over in the past 12 months. In Michigan, this translates to more than 786,000 households. The average age of a caregiver for someone aged 50+ is 46 years old.

Spouses are the first source of caregiving assistance, followed by adult children. Eighty-five percent of all home care of older people is provided by family, and 71% of all long term care is provided in the community.

Caregiver Profile

The typical caregiver is female; however, increasingly males-primarily spouses-are engaged in caregiving tasks. The older the care recipient, the older the caregiver.

- Elderly people are increasingly more likely to be caregivers.
- Caregiving is typically not a shared activity. Studies have found that one person tends to provide the majority of assistance, while secondary caregivers assist on an intermittent basis.
- Caregivers tend to live close to care recipients. At least 20% share a household and 55% live less than 20 minutes from the care recipient.
- Within minority and ethnic groups, caregiving occurs at a higher incidence than other groups. Caregivers of Asian-American, African-American and Hispanic households are more likely to be caring for more than one person, to live with a care recipient, and to receive help from other family members.

Caregiving encompasses many activities, ranging from transportation and shopping to daily personal care assistance. Male caregivers tend to assist with activities such as home repair and financial management, while females tend to address housekeeping and personal care needs.

Most caregivers do not plan for caregiving, despite the fact that caregiving has become a normal event in today's life span. Caregivers tend to "take one day at a time" and not seek out information until they need it. This presents a challenge to those designing activities to educate caregivers. Caregivers often are only interested in a solution when faced with a caregiving problem, and are hesitant to consider their future needs as caregivers. Caregivers also tend to slip into caregiving; it often starts as intermittent assistance and gradually evolves into a daily routine.

There are distinct differences in caring for someone who is physically frail but cognitively intact, and someone who has cognitive deficits resulting from a disease, such as Alzheimer's Disease. People with dementia often engage in disruptive behaviors and eventually require 24-hour supervision. Those who are cognitively intact may be demanding or frustrated by their physical limitations, yet still capable of participating in caregiving decisions and clearly communicating their needs. The needs of caregivers will vary according to the type of care provided.

It is often assumed that caregiving is a stressful responsibility. Many caregivers, however, enjoy the caregiver role and its challenges. Several studies have looked at caregiver support and found it is how the caregiver perceives his/her role and whether he/she feels supported that often makes the difference. Knowing that help is available is often as supportive as using the help.

Caregiving: Recent Activities.c.Caregiving: Recent Activities;

In the past few years, several significant activities have contributed to the discussion of caregiving issues.

March 2000 A Commission on Services to the Aging subcommittee on caregiving presented its briefing paper to the Commission. The paper recognized the role of the family caregiver as pivotal in maintaining the older person at home. The subcommittee acknowledged the growing trend of older caregivers, many of whom care for spouses, parents and even adult children. While caregivers face continual demands, caregiving can be a deeply rewarding experience for those who are able and willing to meet those demands.

June 2000 The Michigan Long-term Care Work Group issued its report on long term care reform, citing the significant contributions of family caregivers in the array of community based long term care. The work group identified respite and day care services as desirable supports for caregivers. The report resulted in the allocation of additional state funds for respite and adult day care services through OSA, which increased the number and capacity of adult day services assisting caregivers.

December 2000 The Older Americans Act was re-authorized by Congress to include the establishment of the National Family Caregiver Support Program (NFCSP) in Title III-E (see Appendix B). With funding available in Fiscal Year 02, the NFCSP called for a shift among the aging service providers from solely a care recipient focus to one which includes the caregiver.

September 2001 OSA convened its first Caregiving Summit to address caregiver issues and programs. Triggered in part by the National Family Caregiver Support Program, OSA sought to bring key organizations with an interest in caregiving together, including those outside of the traditional "aging network." Four important points emerged as part of the Summit:

- **information and assistance (I&A) are critical to caregivers;**
- **caregivers themselves need to be identified earlier;**
- **physicians play an important role with caregivers; and**
- **respite care services must be addressed through collaboration.**

June 2002 The State Advisory Council on Aging received its directive from the Michigan Commission on Services to the Aging. The Commission identified three major topics of interest: caregiving, guardianship and financial planning. Commissioner Hoelzel-Seipp, Council Chairperson, asked Council members to discuss these issues; it was decided that all three were linked and that the Council would begin by addressing caregiving.

August 2002 With a focus on caregiving, the August meeting featured a panel of experts in caregiving programs. Council members heard from Bonnie Graham, OSA; Dan Doezema, OSA/formerly with the Department of Community Health; and Ilene Orlanski, Greater Michigan Chapter of the Alzheimer's Association. OSA staff discussed the National Family Caregiver Support Program funded through the Older Americans Act and gave a national overview of state-level caregiver support programs. Dan Doezema discussed the caregiver support programs for people caring for relatives with dementia. The Alzheimer's Disease Chapter representative described some of the caregiving challenges in dementia care.

September 2002 The success of the first summit led to a second Caregiving Summit held in Fall 2002. This event featured Dr. Rhonda Montgomery and Dr. Carol Barrett. Dr. Montgomery's latest research on caregivers has led to the development of a framework for the identification of caregivers. The "seven markers of caregiving" describe family members' variations in recognizing their assistance as caregiving. Dr. Barrett facilitated discussion among the participants.

November 2002 The Council received an update of the OSA Caregiving Summit II, held in September. Considerable information about caregiving issues was shared at the summit, specifically about recent research findings and a conceptual framework designed to assist aging service providers in understanding the role of caregivers and how people perform the role.

This was followed by a presentation given by Dr. Carol Barrett on her study, "Connecting with Caregivers." Her findings included:

- caregivers lack awareness of services;
- fail to recognize that useful services are available; and
- typically rely upon friends and family for information about services.

She interviewed caregivers who were using services such as home health aides or day care/respite. Caregiving studies provide a better understanding of the role and activities undertaken by family members as they become caregivers. Such information assists agencies in planning and providing caregiver support programs.

January 2003 The Council received an update on the Information and Assistance Work Group convened by the Office of Services to the Aging to review and revise the service standard for information and assistance services. The remaining meeting time was used to develop the Council's recommendation. Council members discussed the various caregiving issues, compiled previous summaries and assigned priority to proposed recommendations. In winnowing through the many potential recommendations, a clear commitment to the needs of the caregiver emerged, and that commitment is reflected in this report's recommendation.

March 2003 With the development of a consensus recommendation, the Council turned its attention to the report. Members were provided a draft copy for review and comment during March. The majority of the members provided comments on the draft report which were incorporated into the final report.

Caregiving: State Advisory Council Discussion.c.Caregiving: State Advisory Council Discussion;

In formulating the Council's recommendation, several themes emerged: the importance of available and reliable information for caregivers; the feasibility of some financial incentive/benefit to caregivers and businesses which support caregiving; an increased awareness about caregiving among human service agencies, elected officials and the public. Like caregiving itself, support for caregivers must be flexible and varied in approach. Caregiving is not a "one size fits all" situation.

As discussed in the Council's previous two annual reports, Information and Assistance (I & A) services are critical components for linking caregivers with services. It is often a caregiver who seeks formal services; the availability of accurate, timely and adequate information is critical. The role of technology is increasingly important as web-based resources, such as the OSA web site, are often used by adult children with easy access to computer technology. The 24/7 accessibility of web-based information is attractive to busy adults and valuable to out-of-state family members. Demand for this type of assistance will likely increase, so information must be kept current and accurate. There was strong support among Council members for further development of a web-based aging information network using the OSA web page as the "anchor" with regional web page links.

The Council discussed the "single point of entry" concept for caregiver support and information. The "single point" is only effective if people know how to find it and what to expect. During the past year, planning for the implementation of the 2-1-1 system for human services has made progress. The 2-1-1 system is a human services referral system which provides callers with information about human service agencies and programs in a geographic area. The national effort to establish 2-1-1 systems is a valuable means of linking caregivers with service information.

In addition to service information, members cited the value of counseling and support group referrals. The stress of caregiving can be alleviated by connecting with others in similar situations. Some of these supportive activities have been developed with National Family Caregiver Support Program funds.

The Council members considered payments, incentives and other financial considerations for caregivers and their employers. They discussed the possibility of direct payments to caregivers, tax breaks for individual caregivers, and tax incentives for businesses that provide employees with caregiver support. A national estimate by the Center for Medicaid and Medicare Services (CMS) states that if informal caregivers were to be replaced with paid home care, it would cost between \$45-75 billion per year. While the Council supports direct caregiver benefits, in the current economic situation, caregiver payments or financial incentives are not feasible.

Throughout the Council discussions, members kept returning to the unique experiences of caregivers. It was generally agreed that human services agency staff, e.g., Family Independence Agency, aging service providers, and the majority of elected officials, e.g., legislators, county commissioners, do not fully appreciate the difficulties faced by caregivers and often overlook caregiver needs in their efforts to assist care recipients. When funds become available, the Council supports a caregiver media campaign similar to the OSA long term care awareness campaign.

In conclusion, the Council recommends that the Commission increasingly focus on caregiver needs in addition to those of the care recipient. The Council believes the following areas are essential components to supporting caregivers:

- 1. Assist caregivers to identify themselves as such**
- 2. Identify what the caregiver can expect**
 - a. from the care recipient;**
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APPENDIX A

Change, Continuity and Diversity Among Caregivers Executive Summary

Over the past few decades, research and program experience around family caregiving has shown that caregivers are very diverse in the manner in which they provide care and the consequences that they experience. The types and intensity of tasks that caregivers perform vary dramatically, depending upon the familial role of the caregiver. Evidence suggests that familial roles also influence how care is provided. The variability in caregiving behaviors indicates that the caregiving experience is significantly different for different types of caregivers. This paper highlights the diversity of caregiver experiences and provides a conceptual framework for program planners and administrators to better understand the implications of this diversity for the design and implementation of caregiver support services.

The "marker" framework discussed in this paper captures caregiving as a dynamic process and serves as a tool to gauge shifts in caregiving stages and receptivity to services and supports. The seven markers of this caregiving trajectory include: 1) performance of initial caregiving task; 2) self-definition as a caregiver; 3) provision of personal care; 4) seeking out or using assistive services; 5) consideration of institutionalization; 6) actual nursing home placement; and 7) termination of the caregiver role. The order and timing of markers 2 through 5 are considered defining characteristics of the caregiver experience and have direct relevance for implementing caregiver support programs. An important consideration is that the order and timing of these markers varies depending on the individual and type of caregiver (e.g., spouse versus adult children caregivers). In addition to the type of caregiver, an individual's culture may play a significant role in the spacing of these markers.

Several implications for program design and delivery are presented. A key consideration for the Aging Network is the importance of creating multiple services that are flexible to meet the full range of needs of the community being served. In addition, states should be cognizant of limited resources and create services for the most prevalent types of caregivers in their community. Also, effective targeting and marketing of services should be used in order to reach caregivers at the "servable moment" point, not after it is too late. In offering respite, for example, only when caregivers reach the point at which they are providing extensive care and have identified themselves as caregivers will they reach the point of receptivity (the "servable moment") to respite programs. Strategies to increase receptivity should be based on the understanding that different types of caregivers arrive at the "servable moment" for different reasons and that caregivers use services only when they perceive the benefits to outweigh the monetary, emotional, or physical costs of using the service. Lastly, programs should create institutional links between service providers in order to assist the caregiver in identifying services that best meet their needs at any point in the caregiving trajectory. This will enable a program to contend with the changing nature of the caregiving role. In the future, providers will be far more effective in their support efforts if they acknowledge and target both the diversity and the consistencies that social contexts create.

Authors: Rhonda J. V. Montgomery, Ph.D., Director, Gerontology Center, University of Kansas and Karl D. Kosloski, Ph.D., University of Nebraska at Omaha. Administration on Aging, 2001.

Change, Continuity and Diversity Among Caregivers

Executive Summary

Over the past few decades, research and program experience around family caregiving has shown that caregivers are very diverse in the manner in which they provide care and the consequences that they experience. The types and intensity of tasks that caregivers perform vary dramatically, depending upon the familial role of the caregiver. Evidence suggests that familial roles also influence how care is provided.

APPENDIX B

National Family Caregiver Support Program.c.:National Family Caregiver Support Program;

The National Family Caregiver Support Program (NFCSP) was established as Title III-E of the 2000 amendments to the Older Americans Act. Congress implemented the program in fiscal year 2001 with a \$125 million appropriation. During FY 2002, more than \$141 million was allocated nationally to support the program. Michigan's FY 2002 Title III-E NFCSP allocation from the Administration on Aging was \$4.3 million.

While the network has always recognized family and other informal caregivers, the NFCSP allows caregivers to be served as a new clientele with distinct and separate needs.

All NFCSP funds must be allocated to area agencies on aging through the approved intrastate funding formula. Local area agencies on aging are responsible for determining what caregiver services will be available within their planning and services area.

State units on aging cannot reserve funds for activities at the state level or conduct caregiver demonstration projects in particular areas of the state. However, a state unit on aging may use an amount equal to 5% of the Title III-E funds allocated to the state expenditures for grandparent and older relative caregivers of children, up to the maximum of 10% allowed by law, and may design intrastate funding formula allocations that vary the proportion of funding among area agencies on aging.

Five categories of service*:

1. Information to eligible caregivers about eligible services.
2. Assistance to eligible caregivers in gaining access to services.
3. Individual counseling, organization of support groups (capacity-building), and caregiver training to eligible caregivers to assist caregivers in making decisions and solving problems relating to their caregiving roles.
4. Respite care to temporarily relieve caregivers from their caregiving responsibilities.
5. Supplemental Services, on a limited basis, to complement the care provided by eligible caregivers (suggested to be no more than 20% of the allocated federal funding).

* Eligible grandparent and other older relative caregivers may receive service from all five categories.

Priority for Service - In providing services to a family caregiver, grandparent or older individual who is a relative caregiver, priority must be given to older individuals with the greatest social need; older individuals with the greatest economic need; and older individuals providing care and support to persons with mental retardation and related developmental disabilities.

Local Match - Federal share of developing and implementing the National Family Caregiver Support Program in each state shall not exceed 75%. State and local resources shall provide the 25% non-federal share of program costs.

Limitation - A state may not use more than 10% of the total federal and non-Federal share of the funds available to provide support services to grandparents and older relative caregivers of children.

National Competitive Grants - Five percent of the total program allocation is reserved at the national level for competitive innovation grants and activities of national significance such as program evaluation, training, technical assistance and research. The purpose of these grants is to assist in the development of multifaceted systems of caregiver support. States are likely to be one of the preferred grantees with incentives to include area agencies and others as partners.

OSA has specific requirements for implementation of the NFCSP in Michigan.

- **Given the availability of tobacco settlement and escheat funds to support respite and adult day services in Michigan, area agencies on aging were strongly encouraged to explore new and innovative strategies for meeting the needs of caregivers within their planning and service areas/regions. Many area agencies on aging have conducted public hearings, focus groups and community forums to learn about caregiving needs in their local communities.**
- **Area agencies on aging were required to budget not less than \$25,000 or 5%, whichever was less, but no more than 10% of their Title III/E allocation to support grandparent and other older relative caregivers.**
- **All area agencies on aging were required to establish at least one community focal point for caregivers in the planning and service area/region. At least one of the caregiver focal points established in each region must be an adult day services program or senior center.**

OSA has developed three statewide service standards for implementation of the NFCSP. The services include: Kinship Respite Care; Caregiver Supplemental Services; and Caregiver Education, Support and Training.

APPENDIX C

Presentations to the State Advisory Council

Carol Barrett, Ph.D.
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MI Commission on Services to the Aging
Owosso, MI

Commissioner Louise Thomas
MI Commission on Services to the Aging
Kentwood, MI

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Linda Haywood, Deputy Director
Eric Berry
Linda Kimball
Office of Services to the Aging

Community Services Division:
Holliace Spencer, Director
Amy Bryon, Student intern
Jane Church
Bonnie Graham
Heather Jones
Laura McMurtry
Julia Thomas

Research, Advocacy and Program Development Division:
Cherie Mollison, Director
Heehyul Moon, Student intern

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